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## Care giver burden among spouse of psychiatric patients attending psychiatry outpatient department of a teaching hospital

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### Abstract

**Introductions:** Caregiver burden in mental illness is a global issue. Burden is more significant and high among spouse than other caregivers. Spouse face illness-specific burdens of feeling powerlessness, fear, marital stress and partnership and family roles.

**Methods:** A cross-sectional study was conducted in outpatient department of psychiatry in Patan hospital, Patan Academy of Health Sciences, Nepal, from 26<sup>th</sup> August to 23<sup>rd</sup> September, 2018. Non-probability purposive sampling technique was used. Data was collected from spouses of psychiatric patients by face-to-face interview using Burden Assessment Schedule (BAS) to assess the caregiver burden of spouses of psychiatric patients.

**Results:** Out of 160 spouses interviewed, 94 (59%) had severe burden, 13 (9%) very severe, and 53 (34%) moderate. Burden was significantly associated with respondents' relation to patient, educational status, income and diagnosis. The respondent's age, occupation, duration of caring, and place of residence had no significant association with burden.

**Conclusions:** More than half of the spouses of psychiatric patients had severe care giver burden.

**Keywords:** burden, psychiatric patient, spouse

## Introductions

Mental illnesses are rising worldwide.<sup>1</sup> It is a top cause of global burden of disease.<sup>2</sup> It affects individuals as well as their caregivers.<sup>3</sup> The burden of care, usually falls on the spouse in marital relationships.<sup>4</sup> Living with and caring for psychiatric spouse is an enduring stressor and causes considerable burdens.<sup>5</sup> Caregiver burden refers to strains and difficulties experienced by the caregiver of mentally ill patient and include a range of psychological, emotional, social, physical, and financial problems.<sup>6</sup>

The prevalence of care giver burden for spouses is high.<sup>7</sup> In India overall care giver burden for spouse was 54%, majority had experienced severe to extremely severe burden.<sup>8</sup> In Nepal, married caregiver felt higher burden than unmarried.<sup>9</sup>

This study aims to assess the burden among spouses of psychiatric patients, the domains and factors associated with the burden.

## Methods

A quantitative, cross-sectional study was conducted in psychiatry outpatient department of Patan hospital, Patan Academy of Health Science (PAHS), Lagankhel, Lalitpur, Nepal. Non-probability purposive sampling technique was used. Sample size was calculated by using prevalence of caregiver's burden.<sup>10</sup>

The data collection instruments consisted of two parts.

Part I: Socio demographic Questionnaire -9 questions- 1) Type of diagnosis 2) Respondent relation to patient 3) Completed age 4) Educational status 5) Type of family 6) Occupation 7) Husband/wife income 8) Duration of caring 9) Permanent address and temporary address.

Part II: Burden Assessment schedule (BAS)<sup>11</sup> developed & standardized by step wise ethnographic exploration method in India. The inter-rater reliability and content validity are

high 0.80. Criterion validity was established by comparing with Family Burden Interview Schedule ranging between 0.71-0.82. Nepal and India share similar socio-cultural aspects. Forward and back translation of the instrument was done by utilizing the guideline Wild et al. 2005.<sup>12</sup> Reliability of the tool was maintained by Cronbach's coefficient (r) is 0.86.

The ethical clearance was obtained from Institutional Review committee of (IRC) of PAHS. Permission was taken from Hospital director, Nursing director, head of department of psychiatry department and OPD in-charge of Patan hospital.

Informed verbal and written consent was taken and face-to-face interview was conducted. Data analyzed using the Statistical Program for Social Science version 16. Inferential statistics (Chi-square test) was used to determine the association between variables. Level of significance was set at 0.05.

## Results

There were 160 respondents. Mean burden score was  $86.03 \pm 10.58$ , and 56 (35%) caregiver were in age group 40-49 years ( $41.01 \pm 10.30$ ). Eighty six (54%) of the spouses were husband; 54 (34%) respondents had basic level of education; 3 (2%) had master degree; 103 (65%) living in nuclear family; 29 (19%) had job and 61 (39%) had other occupation (driver, tailor, singer etc.), 59 (39%) had income of NPR 10,000 to 20,000 per month and the mean duration of caring was  $3.78 \pm 5.04$  years, 75 (47%) had duration of caring of 6-11 months. Diagnosis of 44 (28%) of respondent's spouse was neurotic, stress-related & somatoform disorders.

In 94 (58.75%) the level of care giver burden was severe, Table 1; highest maximum score of 10 was obtained in the domain of physical and mental health, Table 2. The care giver burden was significantly associated with relation to patient, Table 3; income, Table 4; and diagnosis, Table 5.

**Table 1. Level of burden among spouse of psychiatric patient (n=160)**

| Level of burden                       | Frequency | Percentage |
|---------------------------------------|-----------|------------|
| Mild burden (41-60)                   | -         | -          |
| Moderate burden (61-80)               | 53        | 33.13      |
| Severe burden (81-100)                | 94        | 58.75      |
| Very severe burden (101-120)          | 13        | 8.13       |
| Mean score $\pm$ SD=86.03 $\pm$ 10.58 |           |            |

**Table 2. Mean score & Standard deviation of each domain of Burden Assessment Schedule (n=160)**

| Domains                  | Total no. of items in the domain | Minimum score of each domain | Maximum score of each domain | Mean  | SD   |
|--------------------------|----------------------------------|------------------------------|------------------------------|-------|------|
| Spouse related           | 5                                | 6.00                         | 13.00                        | 9.13  | 1.50 |
| Physical & mental health | 6                                | 6.00                         | 18.00                        | 11.34 | 3.35 |
| External support         | 5                                | 5.00                         | 15.00                        | 9.49  | 2.39 |
| Caregiver's routines     | 4                                | 5.00                         | 11.00                        | 8.14  | 1.27 |
| Support of pt.           | 3                                | 3.00                         | 9.00                         | 6.40  | 1.10 |
| Taking responsibility    | 4                                | 5.00                         | 12.00                        | 9.80  | 1.21 |
| Other relations          | 3                                | 3.00                         | 9.00                         | 4.84  | 1.72 |
| Patient's behaviour      | 4                                | 4.00                         | 12.00                        | 7.88  | 2.41 |
| Caregiver's strategy     | 4                                | 5.00                         | 12.00                        | 8.53  | 1.36 |

SD: Standard Deviation

**Table 3. Association between Sociodemographic Characteristics (Age, Respondent relation to patient, Educational status, Type of family) of Spouse of psychiatric patient and level of burden (n=160)**

| Variables                       | Moderate burden<br>n (%) | Severe & very severe burden<br>n (%) | Chi-square<br>(x <sup>2</sup> ) | p-value |
|---------------------------------|--------------------------|--------------------------------------|---------------------------------|---------|
| Age (in year)                   |                          |                                      |                                 |         |
| 19-39                           | 25 (36.23%)              | 44 (63.77%)                          | 5.29                            | 0.46    |
| 40-79                           | 28 (30.77%)              | 63 (69.23%)                          |                                 |         |
| Respondents relation to patient |                          |                                      |                                 |         |
| Husband                         | 41 (47.67%)              | 45 (52.33%)                          | 17.76                           | 0.00*   |
| Wife                            | 12 (16.22%)              | 62 (83.78%)                          |                                 |         |
| Educational status              |                          |                                      |                                 |         |
| Basic level                     | 27 (27.27%)              | 72 (72.73%)                          | 7.88                            | 0.01*   |
| Secondary level                 | 16 (35.56%)              | 29 (64.44%)                          |                                 |         |
| Higher level                    | 10 (62.50%)              | 6 (37.50%)                           |                                 |         |
| Type of family                  |                          |                                      |                                 |         |
| Single                          | 31 (30.10%)              | 72 (69.90%)                          | 1.19                            | 0.27    |
| Joint                           | 22 (38.60%)              | 34 (61.40%)                          |                                 |         |

P value &lt;.05=significant

\*significant

**Table 4. Association between Sociodemographic Characteristics (Type of occupation, Husband/Wife income per month, Permanent address and Temporary address) of Spouse of psychiatric patient and level of burden, n=160**

| Variables                           | Moderate burden n (%) | Severe & very severe burden n (%) | Chi-square (x <sup>2</sup> ) | p-value |
|-------------------------------------|-----------------------|-----------------------------------|------------------------------|---------|
| Type of occupation                  |                       |                                   |                              |         |
| Agriculture                         | 24 (32.88%)           | 49 (67.12%)                       | 0.04                         | 0.95    |
| Job                                 | 29 (33.33%)           | 58 (66.67%)                       |                              |         |
| Husband/wife's income/month (n=152) |                       |                                   |                              |         |
| <20 thousands                       | 27 (27.00%)           | 73 (73.00%)                       | 4.60                         | 0.03*   |
| >20 thousands                       | 23 (44.13%)           | 29 (55.77%)                       |                              |         |
| Permanent address                   |                       |                                   |                              |         |
| Municipality                        | 46 (33.82%)           | 90 (66.18%)                       | 0.20                         | 0.65    |
| Metropolitan                        | 7 (29.17%)            | 17 (70.83%)                       |                              |         |
| Temporary address(n=70)             |                       |                                   |                              |         |
| Municipality                        | 12 (38.71%)           | 19 (61.29%)                       | 0.21                         | 0.64    |
| Metropolitan                        | 13 (33.33%)           | 26 (66.67%)                       |                              |         |

P value &lt;.05=significant

\*significant

**Table 5. Association between Caregiving information and Clinical Characteristics of spouse (duration of caring and Diagnostic category) of Spouse of psychiatric patient and level of burden (n=160)**

| Variables  | Moderate burden n (%) | Severe & very severe burden n (%) | Chi-square x <sup>2</sup> | p-value |
|--|-----------------------|-----------------------------------|---------------------------|---------|
| Duration of caring                               |                       |                                   |                           |         |
| <5 year  | 44 (35.77%)           | 79 (64.23%)                       | 1.68                      | 0.19    |
| >5 year  | 9 (24.32%)            | 28 (75.68%)                       |                           |         |
| Diagnostic category                              |                       |                                   |                           |         |
| Substance use disorder                           | 4 (10.26%)            | 35 (89.74%)                       | 14.73                     | 0.05*   |
| Schizophrenia, schizotypal & delusional disorder | 6 (27.27%)            | 16 (72.73%)                       |                           |         |
| Mood disorders                                   | 17 (43.59%)           | 22 (56.41%)                       |                           |         |
| Neurotic stress-related & Somatoform disorders   | 18 (40.91%)           | 26 (59.09%)                       |                           |         |
| Others*  | 8 (50.00%)            | 8 (50.00%)                        |                           |         |

Others\*Organic mental disorder, migraine headache, epilepsy

P value &lt;.05=significant

\*significant

## Discussions

In this study mean burden score was  $86.03 \pm 10.58$ , less than the findings of study conducted in India<sup>13</sup> in 2018 with mean score of  $73.5 \pm 14.0$  and study from Nepal<sup>9</sup> in 2015 with score of  $71.78 \pm 6.56$ . Similarly, another study conducted in 2015 in Iran has contradictory findings that revealed that the mean average score to be  $51.73 \pm 18.23$ .<sup>14</sup>

In this study, spouse felt highest burden on the domains like physical and mental health (mean score of  $11.34 \pm 3.35$ ) followed by taking responsibility (score  $9.80 \pm 1.21$ ) but lowest burden on relations (score  $4.84 \pm 1.72$ ). The study from India reports similar findings with maximum burden in the domains of physical

and mental health ( $7.48 \pm 1.74$ ) followed by external support ( $6.81 \pm 1.60$ ), caregiver routine ( $5.62 \pm 1.02$ ), taking responsibility ( $5.43 \pm 1.53$ ).<sup>15</sup> Another study from India also supports present study findings that the highest amount of burden was in areas of physical and mental health ( $11.98 \pm 3.27$ ), spouse related ( $9.90 \pm 1.86$ ), and external support ( $9.40 \pm 2.57$ ).<sup>16</sup>

In this study, significant association was seen between severe and very severe burden score and wife as a care giver, having basic level of education, income of less than NPR 20,000 and patient diagnosed as substance use disorder. Similar findings were reported from study conducted in India where female spouses reported slightly higher level of burden than

male, those from lower socioeconomic status, those from rural areas but no significant association to the type of family.<sup>13</sup>

Similarly, a study conducted in Nepal in 2015 shows that no significant difference between level of burden and educational status, socioeconomic status, duration of care and type of illness.<sup>9</sup> Another study conducted in India in 2016 showed that clinical diagnosis did not elicit any statistically significant difference indicating no difference on burden experienced by the spouses based on the clinical diagnosis.<sup>17</sup> Another study conducted in India in 2014 had contradictory findings to present study that there was association between area of living and level of burden.<sup>18</sup>

Limitations of present study includes single center tertiary care university teaching hospital in urban Kathmandu valley, the capital city of Nepal, and may not represent the population in general.

## Conclusions

More than half of spouse of psychiatric patients had severe level of care giver burden. Female spouse, those who were less educated and income less than twenty thousand per month had higher burden.

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## Conflict of interests

None

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